

SUMMARY OF ADVISORY COMMITTEE MEETING

Virginia Early Hearing Detection and Intervention Program

Virginia Department of Health

December 9, 2011

Draft

The following persons attended the meeting: Ann Hughes, Brian Campbell, Callie Beasley, Christine Eubanks, Christine Evans, Daphne Miller, Darlene Donnelly, Debbie Pfeiffer, Deana Buck, Frank Aiello, Bob Boyle, Leslie Ellwood, Evie Frazier, Heather Strang, Jamie Lawson, Kathleen Moline, Ken Henry, Lisa Powley, Nancy Bond, Rebecca, and Valerie Luther

Membership and Introductions:

Evie Frazier, UVA Developmental Pediatric Fellow

Department of Medical Assistance Services (DMAS)

Brian Campbell of DMAS had been informed by Lisa Powley of the Hearing Aid Loan Bank that the highest utilization of the Loan Bank came from medicaid enrollees. (About 60%) His response is that since Medicaid enrollees have a hearing benefit he would like to prohibit them from using the Hearing Aid Loan bank. They present a steady drain on its limited resources. It was his recommendation that the bank be used only when the child is referred for a cochlear implant

Virginia Hearing Aid Loan Bank (VHALB)

Lisa Powley presented for the Hearing Aid Loan Bank. Altogether 572 children from the day we began up to November 20, 2011 have benefited from this program. So far this year we have already sent out 248 aids and 7 FM systems.. The budget only has \$5,000 to last until June 30. Something has to be done about funding or Medicaid approval or we will not be able to pay audiologists after March 2012. Audiologists get \$200 for fitting. Could they bill Medicaid? If so, can Medicaid be billed for a second fitting?

Christine Eubanks asked why there were so many Medicaid applicants at the Loan Bank. Brian stated Virginia Premier was not approving permanent hearing aids until the child had a trial with a loaner. The trial provided Va Premier with the justification they needed to provide a permanent hearing aid. What happens with some placement criteria is that providers develop their own internal process which is different from other regions. So as long as the audiologist provides them with that information, a trial is not needed.

Eubanks stated VCU had not been getting approval for fitting and dispensing fees for many years but Brian said that changed in 2008 and it is being done now. Lisa felt they must change the application for the Hearing Aid Loaner Bank. If child has Medicaid or FAMIS they should not be using the bank unless it is a candidate for a cochlear implant. Lisa Powley stated the Loan Bank's rate for a loaner fitting is \$100 per ear per device. Medicaid pays \$76.50 per ear dispensing fee and device fees. A letter will be sent out informing people of the changes

Hearing Workgroup

Eubanks spoke on the Workgroup. Their focus is activities to increase follow up. The group has recently become the steering committee for Guide By Your side because things are changing there and it needs a particular direction. It was decided to have both meetings on same day. Meet as workgroup adjourn and meet as Steering Committee

Virginia Network of Consultants (VNOC)

VNOC works with deaf and hard of hearing children. The consultants are those who have been identified as having expertise in deafness. They are from all over state. School divisions and state agencies with questions can call for help with a child. It has had 19 referrals as of today. All have been requests from school divisions. In addition to VNOC, Ann reported on Virginia's chapter of Hands & Voices. At the last Hearing Workgroup meeting they discussed Hand & Voices. They have had a shaky start getting a chapter going in Virginia. *The Communicator* is a quarterly publication put out by Hands & Voices. Ann Hughes offered at the September EHDI Advisory Committee meeting to try to get this to every member of *The Communicator*. She distributed 20 copies at today's meeting. She called attention to the story of Bailey V. Clark on the front cover. Bailey is now the acting director of Virginia Hands & Voices.

On back of *The Communicator* is a form for membership. If someone in Virginia joins then the money stays in Virginia rather than going to the National organization. Eubanks looked at other state chapters to see how the fee was done. Chapters are not required to be uniform in their pricing. In this grant cycle, Ruth built in funds for Guide By Your Side guides and any family matched through guides to get membership in Hands & Voices. The VA H&V Advisory Board will explore having a fund raising drive once the holidays are over.

Partnership for People with Disabilities

Dena Buck has posted four modules and two are on hearing, 123 Process and Hearing Loss. These two modules have the greatest number of hits. She would like to add additional content regarding home visiting and ENTs'. Ruth thinks hearing 101 could provide a great foundation. It is an interactive module. Virginia is recognized as the national leader in home visiting work. Ruth wants some tracking data and would like a small group that could help institute that as our next project. Information on home visits could be added to the website.

Kathleen felt timing for this was good because there are 3 nationally based programs along this line getting established in Virginia. The Home Visiting Consortium is 10 state wide programs that would independently provide home visits that now wants to come together and work as a group.

Deane Buck stated she was concerned about the amount of misinformation about EHDI. When they start work on the module for Home Visitors they would like the committees' assistance in what goes into the module and how it will be presented. The Partnership is having discussions with Ruth about interviewing families lost to follow up to find out about their experiences and to families of children whose time line was delayed.

Christine Evans stated she was at an A G Bell meeting. They would like to do an event showcasing the early intervention track we are defining. This would not be until late June 2012 and hopefully we will have more modules by then to include.

Department of Education (DOE)

Debbie Pfeiffer stated that because of budget cuts, VDOE had to reduce the amount of several grants they are funding this year. Part II of the INSITE Training was held in September for people providing early intervention services and people who are early childhood educators, for teachers of blind/deaf. The 6-day training was funded by VDOE and sponsored by the VA Project for Children and Young Adults with Deaf-Blindness, VCU. The event went well. DOE hosted Part II of the National Summit on Deaf Education, and it was attended by reps from many state agencies. The video series developed by Dr. Emmet Jones of the Challenge Discovery Projects are now on line. There are a total of 18 which includes 12 sign language sessions based on the daily routine of the child. To find the videos on their website, refer to either the Parent Child Advocate button (on the left side of their home page) or the sign language instructional videos button (on the bottom right side of the home page).

<http://challengediscoveryprojects.org/>

Public Comment

None

Newborn Screening

Kathleen Moline gave the Newborn Screening report. She explained her program encompassed more than PKU issues. Basically heel sticks are done and the blood spots go to the Consolidated Lab. They evaluate whether the child has critical, abnormal problems and look for genetic metabolic disorders. There are 20,000 babies a year that have some abnormal values. We have been asked to include SKIDS in the panel of tests we do. The Pediatric community wants to know what our Genetic Advisory Committee has to say on that subject. One child in 25,000 might be born with this. The newest thing we are looking at is congenital heart conditions and whether it should be included. It is now a federal recommendation that a child with low oxygen saturation must have an echo cardiogram.

Early Intervention

No update.

Virginia Department of Health (VDH)

The EHDI conference will be held in March 2012 in St Louis. Dr. Frank Aiello, Dr. Leslie Ellwood, Ruth Frierson, and Daphne Miller will attend.

The Guide-By-Your Side Request for Approval of Procurement (RAP) has been approved.

EHDI selected a candidate for the Follow-up Coordinator II position and is waiting on approval to hire.

We are still working on the audiology on line training.

EHDI Educational Materials Review

Daphne distributed some of the educational materials used by EHDI and asked the committee to review them as a group and decide what we want to do. Some of them may need to go in a different direction.

“Can Your Baby Hear” is distributed to the hospital. They fill in the child’s hearing screen results and give them to the parents. It explains the 1 3 6 process for parents. Not all hospitals use it but we need to distribute this information in some manner. It is in the protocols that this information be distributed to the parents. At this time we are not sending them out. The hospitals must download them from our website.

The “Resource Guide for Parents of Children with Hearing Loss” (in English and Spanish) can be downloaded from our website. No funds are available for printing. Daphne was asked to look at the possibility of ASL being included. Several members of the Committee felt we needed the input of families with young children.

The “Loss and Found” DVD was distributed to hospitals and is on YouTube. The hope was it would be played on the CC Tv system for parents.

Deana Buck asked how does EHDI want to get the information out. Evie suggested working with the WIC nurses and tying it in with free things such as a magnet that the parent might hang on to.

Nancy Bond brought up the HIPPA issues.

Kathleen suggested a notice be put on the family’s bill that the child should have follow up testing.

Dr. Ellwood suggested we find a program that does something similar to these suggestions and adapt it to our programs needs.

Debbie Pfeiffer suggested that our poster include a hearing aid on one of the children. Daphne explained we cannot seem to be promoting hearing aids.

It was pointed out we did 2 PSA’s but we don’t where scheduling them for broadcast stands at this time.

Brian pointed out Text 4 Baby can used to send messages up to the age of one year. It is a national program and would have to be reviewed. They would get 3 text messages a week but they are canned. It needs to be reviewed to see when messages are delivered. Kathleen said hearing can be included but we would have to pay for it.

The service is free but the parent has to sign up for it.

Debbie suggested we show “Loss and Found” at regional meetings or wherever it would be the most effective.

“Can Your Baby Hear?” – copies were distributed to the group for people to review and send an email with recommendations. They were asked to look at the CDC hearing loss guide on the CDC website and evaluate it for our use. Christine Eubanks pointed out that parents can get the CDC guide for free, so we might have them fill out the CDC forms before they are discharged and send them in on behalf of the parents.

2012 Meeting Dates:

3/09/2012

6/08/2012

9/14/2012

12/07/2012

Meeting Adjourned at 12:17 pm